Juvenile chronic physical illness in Northern Russia
Studies on mental health, health-related quality of life, and family functioning

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Akademisk avhandling

som med vederbörligt tillstånd av Rektor vid Umeå universitet för avläggande av medicine doktorsexamen framläggs till offentligt förvar i Föreläsningssal A, Psykiatriska kliniken, byggnad 23, NUS, fredagen den 21 mars 2014, kl 09.00.

Avhandlingen kommer att försvaras på engelska.

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ABSTRACT

Background: Chronic physical illness (CPI) is a prolonged, rarely cured condition, which often causes impairment of activities of a child's or adolescent's daily living. This thesis encompasses three cohorts of patients with CPI – diagnosed with diabetes, asthma or epilepsy. Psychological disturbances and difficulties experienced by young patients with CPI are common, and changes in the family environment are inevitable.

Objectives: The overall aim of the study was to assess the psychological well-being of adolescents with CPI in Northern Russia, as well as to identify factors of potential risk or protective significance for adolescents' well-being.

Methods: The questionnaires covering different aspects of psychological well-being as behavior-emotional problems, depressive symptoms, self-esteem and health-related quality of life as well as family functioning were answered by the adolescents with CPI and their mothers, including the Child Behavior Check-List and Youth Self-Report; Beck Depression Inventory; The Rosenberg Self-Esteem Scale; I think I am; Quality of Life in Epilepsy Inventory for Adolescents; Diabetes Quality of Life Questionnaire for Youths; Pediatric Asthma Quality of Life Questionnaire; Self-report Family Inventory; and Socio-Economic Status questions. Disease related clinical information was withdrawn from the pediatric outpatient clinic. The sample consisted of 148 adolescents with CPI identified from Arkhangelsk pediatric outpatient clinic records and their mothers. Comparative data were obtained from a group of 301 schoolchildren and their mothers.

Results: Results in Paper I showed certain differences in mental health of adolescents with CPI compared to healthy counterparts endorsed by mother's reports alone, while self-reports by adolescents with CPI didn't show any discrepancy in the level of behavior/emotional problems and depression compared to healthy peers. Most pronounced symptoms were found in adolescents with asthma and epilepsy associated with disease severity and gender. In the results of Paper II there were no significant differences found in self/mother reported family functioning of the total group with CPI versus controls. The perception of family functioning differed between the CPI groups and was associated to certain disease-related and non-disease factors. Paper III showed that adolescents with diabetes and asthma maintained positive self-esteem similar to or even higher than that of their healthy counterparts. Adolescents with epilepsy reported lower self-esteem compared to other CPI groups or controls. A diversity of factors contributed to self-esteem variation within the CPI groups. Paper IV provided evidence that adolescents with CPI had relatively moderate to high levels of HRQoL. The domains affecting HRQoL were related to both disease-specific (severity) and non-disease factors (gender and SES).

Conclusion: Our findings demonstrate generally low levels of behavior-emotional problems, depressive symptoms, and relatively high self-esteem, positive health-related quality of life, and successful family functioning in adolescent with CPI in Northern Russia. However, there is a risk of mental health problems, particularly of internalizing nature, in adolescents with asthma and epilepsy. The significant risk factors associated with psychological well-being mediated by family functioning in CPI groups were single-parent household, child age, disease severity, child gender, family SES, and changes in the family life. High family competence and successful family functioning are protective factors for psychological well-being in adolescents with CPI.

Key words: chronic physical illness, adolescence, mental health, behavior/emotional problems, depression, self-esteem, health-related quality of life, family functioning